

Occupational aspects of the management of chronic fatigue syndrome/myalgic encephalomyelitis: evidence-based guidance for employers



Introduction

This leaflet summarises the findings of a review of the scientific evidence on the occupational aspects of the management of chronic fatigue syndrome (CFS^{*})/myalgic encephalomyelitis (ME). It is intended for employers and summarises the current evidence on how to support individuals back into, and to remain in work.

What is CFS/ME?

CFS/ME is an illness characterised by disabling post-exertional fatigue (tiredness) and other symptoms, which may include poor concentration, sleep disturbance, headaches, and musculoskeletal pain. These symptoms need to have been present for at least six months, although a presumptive diagnosis may be made much earlier.

CFS/ME affects approximately four per thousand of the population. Although it can occur at any age, it is more common in people in their 20s, 30s or 40s and the illness affects women more than men.

As with other chronic illnesses, some people with CFS/ME may go on to suffer from depression and anxiety. Where these

** Occupational aspects of the management of chronic fatigue syndrome: a national guideline.*
NHS Plus. London 2006.

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occur they should also be treated. Most people who develop CFS/ME are previously healthy individuals with no significant medical or psychiatric history.

A feeling of being 'tired all the time' is very common. Fatigue that persists for several months or more is often referred to as 'chronic fatigue', but without the presence of the other characteristic symptoms, and the careful exclusion of other causes of chronic fatigue, it is not CFS/ME.

Myalgic encephalomyelitis (ME) and post-viral fatigue syndrome are terms that people often use to describe their condition; however many healthcare professionals prefer the term CFS.

Will people with CFS/ME get better?

Published research into CFS/ME suggests that, while few sufferers recover fully, some improve enough to return to work. Around 40% of individuals will improve to some degree over time. Unfortunately, some sufferers deteriorate and become severely affected. Prompt delivery of appropriate management strategies may help to increase the likelihood of recovery and a return to work.

What are appropriate management strategies to facilitate CFS/ME sufferers returning to work?

The therapy options that are described below form part of the management strategy to facilitate return to work.

Cognitive behavioural therapy (CBT) has been shown to be helpful for some individuals but it is not always effective. CBT is a structured form of psychotherapy. The duration of treatment with CBT varies between individuals and is generally undertaken over a period of six to 12 months. CBT is used to assist people to cope with the emotional impact of a variety of illnesses, including cancer.

Graded exercise therapy (GET) also appears to be helpful for some employees. Graded exercise is a carefully structured programme designed to gradually increase aerobic activity. It is a more planned intervention than simple advice to exercise more. If undertaken, it must be supervised by health professionals with experience in GET and given on a one to one basis if possible.

Pacing is a management strategy in which individuals gradually increase their physical and mental activity without exceeding their limitations. People with CFS/ME report that

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they find pacing very helpful but there is only limited published research to show just how effective this is. Pacing is being studied in the UK and the results are due in 2009.

What should an employer do?

If an individual complains of a severe disabling fatigue that is interfering with their work, or has been diagnosed with CFS/ME, you should refer them to an occupational health professional (OHP). The OHP can assist the employee in arranging a management strategy. The OHP will liaise with the individual's GP, consultant or treating practitioner.

You need to ensure that any work issues your member of staff perceives to be contributing to the illness are dealt with. This should cover all aspects of work, including work satisfaction and interpersonal issues.

- In developing a 'return to work plan' the following should be considered:
 - building up work, or work-related skills, at home at first
 - starting with shortened hours and gradually building them up

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- starting with a reduced workload, as above, and gradually increasing it
- ensuring that regular breaks are taken
- ensuring that the individual has a regular review with an OHP.
- Most people with CFS/ME are likely to fall under the remit of the Disability Discrimination Act 1995, where there is a requirement to make reasonable workplace adjustments. These may include measures such as:
 - changing locations of work
 - working from home
 - modifying work hours
 - reducing workloads
 - reducing physical tasks
 - making provision for a wheelchair
 - flexibility in working patterns.

Is ill-health retirement an option?

Ill-health retirement is a possible outcome although it should only be considered once an appropriate management strategy has been considered. Where other conditions such as depression or anxiety are present, they should be treated.

Are there any other factors to consider?

Recovery from CFS/ME is rarely a straightforward process, and there are likely to be times when the individual has a relapse or is not improving. It is important to encourage and support individuals with their management strategy.

Although relapses may occur, some individuals who develop CFS/ME can be helped back to work with a combination of the appropriate treatment and good management. However, anyone severely affected by the illness for a prolonged period of four or more years has a poor chance of recovery and this should be taken into account when reviewing ill health retirement.

Income Protection Schemes

Some employees are able to claim sickness benefits from Insurance Company operated "Permanent Health Insurance" (PHI) policies (also now called Income Protection Schemes). These usually commence after a prolonged period of absence from work – often three months or more.

*For a full version of these guidelines, see
[www.nhsplus.nhs.uk/clinicalguidelines/
index.asp](http://www.nhsplus.nhs.uk/clinicalguidelines/index.asp)*



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